



MAKING A DEVINE DIFFERENCE

April 2021 to March 2022



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Alexander Devine Children's Hospice Service is a charity that provides specialist palliative care and vital support to children with life-limiting and life-threatening conditions, and their families, across Berkshire and into surrounding counties.

The charity was founded in 2007 by John and Fiona Devine in memory of their son Alexander who sadly passed away from a rare brain tumour in 2006. Their personal experience led them to realise there was a desperate need for a local children's hospice service with a hospice facility in Berkshire.

Our mission

Reaching out to
every child and
family who needs us

Our vision

Providing a children's hospice service within Berkshire and into surrounding counties that will give children and families a choice of care and support from a skilled and dedicated team.



150+

children and families
currently supported by
Alexander Devine

Alexander's legacy

2022: celebrating 15 years

Alexander was just four when he was diagnosed with a rare brain tumour. Without a children's hospice in Berkshire, he and his family would have to travel for hours in the car to access the specialist care he needed. These journeys were difficult and often dangerous due to his medical condition.

Alexander endured four and a half years of operations, treatments and therapy, but sadly died at the age of eight.

In 2007, Fiona and John established Alexander Devine Children's Hospice Service and so began their journey to make sure that children, like their son Alexander, and families like theirs would be able to access the support they needed closer to home.

**It all began with
a very special
boy – Alexander**



Alexander



Fiona Devine
CEO and Co-Founder

2021-22 has been a remarkable year for our children's hospice service

Reaching the 15 year milestone for our charity in 2022 has given us the opportunity to reflect on all that has been achieved and consider the positive difference we have been able to make in the lives of hundreds of children and their families.

We wouldn't be in this position without the phenomenal contributions of our community. Thanks to you, together we are changing lives.

We are there for families, giving them access to a choice of specialist care and support. This can be at home, in schools, in hospitals, and in our hospice from Alexander's Care Team, which is made up of specialist nurses, children's carers, family support workers, play specialists, music therapists, and doctors. We help bring families together, make precious memories and ensure they feel supported.

What makes us Devine

Our core values set out what we stand for and what we believe in. Commitment to these values, across all our staff in every team, reinforces our ability to deliver the best possible service for the children and families that depend on us.



Determined



Empowering



**Valuing
Others**



Integrity



Nurture



Empathy

It is our firm belief that every child and family in our community that needs us should have access to the best possible care and support. It underpins our strategic priorities and shapes the growth and development of our children's hospice service.

In the last 12 months our staff have worked tirelessly in all areas of the charity; delivering specialist care and support to more families than ever before and rebuilding and adapting fundraising activities after significant income loss as a result of the pandemic.

A real testament to what we have achieved so far is reflected in our first CQC report of our service since we opened our hospice doors in 2018. I am proud to report that we were rated Good and,

indeed, the CQC identified five areas of outstanding practice. It was especially pleasing to see our team highly praised for their focus and commitment to making a difference and meeting the needs of the children and the whole family.

Over the next year, our attention remains on building our income so we can keep growing Alexander's Care Team to meet the huge demand for our service and cope with the increasingly complex caseload of babies, children, and young people that need our support.

More than ever the generous support of our community will be critical in helping us deliver the care that is needed.

Fiona Devine

Building a
children's
hospice service
for Berkshire

2009

The first Alexander's
Nurse funded



2012

Community
service launched



2007

The Devine family
founded the charity
in memory of their
son, Alexander

2020

Accessible
playground
built.



Continued care
throughout the
pandemic

2021



Overnight respite
established and end
of life care offered at
our hospice

2019

Opened sensory
garden and
hydrotherapy pool



Symptom
Management
service launched



2018

Hospice
doors
opened for
Day care

2013

Launch of
capital appeal



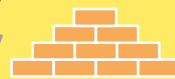
£6 MILLION+ RAISED!

2015

Hospice
groundbreaking



Sibling support and
Specialist play services launched



With your help, we will continue to reach out to
EVERY child and family that needs us

Talia

Talia was born in October 2017 with a number of serious medical conditions. Soon after she was born, doctors gave her parents the devastating news that they were unsure how long she would survive.

Talia spent her first few days undergoing a 'cooling process' to slow brain damage. In the following 12 months, this incredible little girl fought off bacterial meningitis, was diagnosed with cerebral palsy, caught bronchiolitis and underwent heart surgery. She was diagnosed with CHARGE syndrome and vocal palsy and underwent a further operation to be given a tracheostomy. In addition, Talia was pronounced profoundly deaf.

After a whole year of being in the hospital, Talia was finally discharged and able to go home. But with ongoing complex medical conditions, she needs 24/7 care. Alexander's Care Team are able to provide specialist nursing care and give the family the vital support they need to cope with everyday life. Visits to our hospice give Talia the opportunity to do things other children her age would do. There is sibling support for her brothers and her parents have access to the much-needed respite they deserve.



Alexander Devine has enabled us to watch Talia enjoy a new, safe and exciting environment at their hospice, given us respite from her medical demands and most importantly backed us as a family through every step of our journey.

Gemma, Talia's mum



Alexander Devine stepped in and made such an unforgettable impact on our lives. We count our blessings for the continuous support they give us.



When you have a child that is unable to speak and has complex needs, it can be very daunting as a parent to leave them in the care of someone else.

Alexander Devine has been absolutely amazing, we would truly be lost without their support. It is the best feeling that mentally and physically you can rest whilst knowing your child is in extremely safe hands.

Alexander Devine supported parent

What **YOU** have helped us do



17,180+

hours of care delivered



150+

children and families supported



14

children given end of life care in the hospice and in the community



32

families had access to our specialist care for the first time



60+

overnight stays at the hospice



20+

family events including sibling days, fun days and remembrance events



7,040+

hours of respite for families in the community - in families' homes, schools and hospitals



250+ hours

music therapy sessions in our children's
hospice as well as in families' homes



What we have **ACHIEVED**

Growing our service

In the last 12 months, we were able to extend the amount of care delivered to children and families at the hospice and across the community.

We are proud to have delivered:

55% more hours of respite for children and families in the hospice.

30% more hours of specialist care from Alexander's Clinical Nurse Specialists.

19% more hours of respite for children and families in the community.

18% more Day care sessions at the hospice.



thanks to **YOU**

Delivering high quality of care

In March 2022, the Care Quality Commission carried out its first inspection of our service since the hospice opened its doors in 2018. We were rated Good and they identified five outstanding areas of practice, such as:



Staff went the extra mile in their care and were committed to find ways to make a difference to children, young people, and their families.



Staff were focussed on the needs of the whole family and took action to address these needs in a way that was flexible, and person centred.

Inspected and rated

Good



**Care Quality
Commission**

Developing our service to meet family needs

We have grown our Family Support team, established regular parent groups for families to connect, and held our first remembrance events at the hospice.

Choice of care

We opened our Dolphin Suite, a dedicated space at the hospice for end of life care and bereavement support. In November 2021, we provided end of life care for the first time in our hospice.



The Devine Difference: a year of highlights

We want to make a difference in the lives of local children with life-limiting and life-limiting conditions, and their families.

Here are just some of the ways we have done this in the last 12 months.



FOR 32 FAMILIES

It meant they had access to our specialist services for the first time



97% OF FAMILIES

told us that we always have a positive impact on their family's life



42 CHILDREN

benefited from music therapy at the hospice and in the community

CONNECTED FAMILIES

Our Family Support team began monthly coffee mornings at the hospice



20% MORE CARE

We delivered more hours of care in the last year than ever before



INCREASED SUPPORT

In school holidays we increased the number of respite days at the hospice



MAKING MEMORIES

2 remembrance events, 2 Family fun days and more than 15 sibling and joint play days



59 SIBLINGS

supported with specialist play sessions, on their own and in groups



FOR 14 FAMILIES

it meant having our specialist support at the hospice or in their own home for end of life care

Working together to deliver seamless care

We work in close partnership with the NHS, local authorities, and other professionals to deliver the best possible care that is needed for each child and their family.

As part of this, our Clinical Nurse Specialist team has delivered in-person end of life training to the social care team at the Royal Borough of Windsor and Maidenhead and also for children's community nurses across Berkshire, including those at Frimley Health NHS Foundation Trust and Berkshire Healthcare NHS Foundation Trust.

Our Director of Care chairs several groups including the national Children and Young People's Advance Care Planning Network and the Managed Clinical Network for Berkshire, Oxfordshire and Buckinghamshire.

”

I really loved my time working with the team at Alexander Devine. I am so impressed with all the work the team is doing.

Dr Jessica Hudson,
Oxford University Hospitals
NHS Foundation Trust

Looking ahead: our priorities

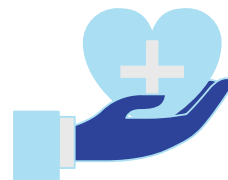
Over the next year our focus will be on maintaining the financial stability of the charity and delivering our three key care priorities:



To extend and develop
our workforce



To maintain and build on
relationships with
colleagues and other
organisations



To ensure meaningful
engagement with
commissioners

Joshua

In November 2021, Emma and Peter's beautiful baby boy Joshua was just five weeks old when he developed meningitis. He sadly passed away at just seven weeks old. In his final days, Joshua and his family were cared for and supported by Alexander's Care Team at our hospice in Maidenhead.

After transferring out of hospital care into hospice care, we very quickly realised that this was absolutely the best place for Joshua and us all, our initial apprehension at leaving a familiar place and people almost instantly gone.

The hospice care was incredible. Firstly they gave us our baby back, we could cuddle him and take him for walks. We were much more a part of his care and gave us a 'home from home' environment that was warm and comfortable but filled with 24 hr support and company through what would be an eight-day long journey.

Our daughter Charlotte was welcomed with toys, a pool, and wonderful people to entertain her, the happiness and well-being of us as a family were seen as a huge priority at that time.

Emma, Joshua's mum



Alexander Devine gave us so much care, support, and happy memories at the worst possible time and for that, we are deeply grateful.

What families told us

We always give families the chance to provide comments and feedback so that we can ensure we meet their needs and develop our children's hospice service accordingly.

A family survey in March 2022, told us how families felt about the specialist care and vital support we provide.



“Staff are very friendly and approachable. I feel safe leaving my children in their care”

97%
said we **always** had a positive impact on their family's life

100%
rated their experience as **Excellent or Very Good**

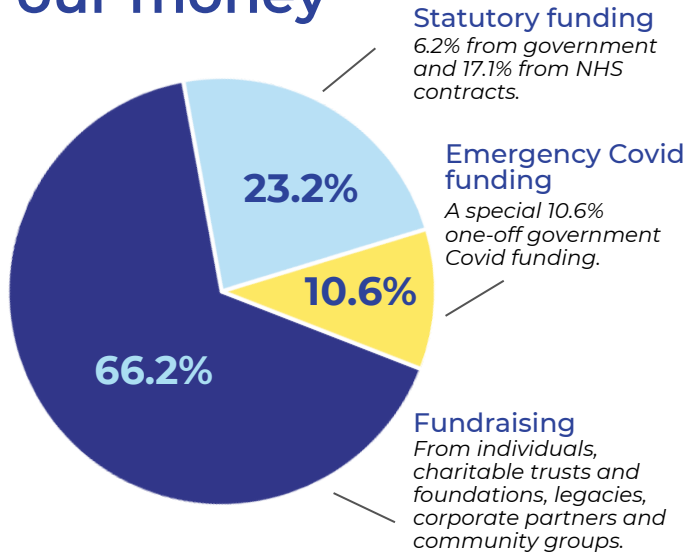
100%
said the hospice was **always** a safe and welcoming environment

94%
said the care we provide **always** or **often** supports their family's needs

“It's an amazing organisation, every single employee we met were amazing to our family....you are very needed and valuable!”

“There aren't the words to say how grateful we are for the support that you provide”

How we **raise** our money

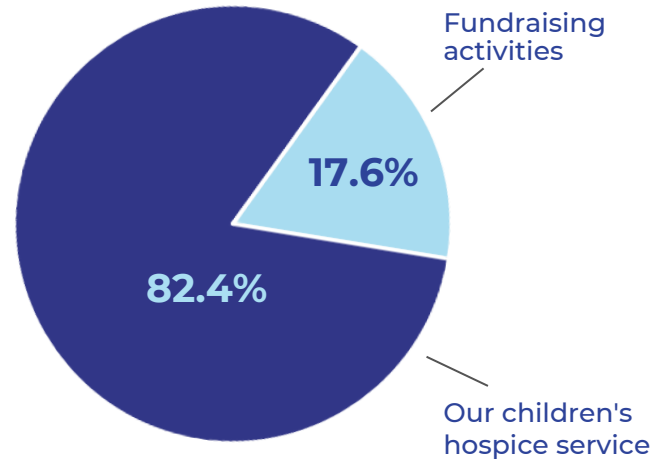


We rely heavily on the generosity of those in our community to help us deliver our specialist care and vital support to children with life-limiting and life-threatening conditions, and their families, across Berkshire and into surrounding counties.

Our income for the year was £2.017 million.*

**This excludes a one-off windfall we received during this period*

How we **spend** our money



For every £1 we spend **82.4pence** is spent on providing specialist care and support.

In 2021-22, the annual cost of running our children's hospice service was £1.74 million.

We could not do it without you!

Here are some fundraising highlights from the last year.



£8k+

APRIL

Special Auction Services organised a charity auction for Alexander Devine



£6k+

MAY

Upton School held its annual charity pedal push



£5k+

JUNE

We were joined by schools and businesses to help us #RockTheBlue for Children's Hospice Week



£17.4k+

JULY

Maidenhead Fundraising Group volunteers opened a pop-up toy shop in Nicholson's Centre



£1.5k+

AUGUST

11 year old Max was our hair-raising hero when he decided to cut his hair



£23K+

SEPTEMBER

Our 12th Heaven Sent Ball returned to De Vere Beaumont Estate



£10.5k+

OCTOBER

21 brave souls took part in our Firewalk challenge at the hospice, including our CEO!



£8k+

NOVEMBER

18 walkers from Daniel Owen walked 13 miles between their offices in Reading and our hospice

We could not do it without you!



£1.5k+

DECEMBER

Supported mum Gemma held a spinathon at her gym, Absolute Fitness in Bracknell



£8.5k+

JANUARY

26 amazing volunteers helped to collect and recycle over 460 Christmas Trees in Maidenhead and Marlow



£289

FEBRUARY

Kind-hearted 10 year old Zoe baked cookies and cakes and sold them at her local church, St Dunstan's in Bourne End



£2.8k+

MARCH

Our volunteer knitters made over a thousand chicks and bunnies for us to sell

We would also like to thank...

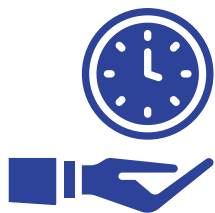
- 💙 All our patrons, trustees, Alexander's Ambassadors and Alexander's Champions.
- 💛 Families whom we support, who have shared their stories and experiences of Alexander Devine to help raise awareness and support our fundraising.
- 💙 All our individual and regular donors, who have helped us to raise vital funds throughout the year.
- 💛 Charitable trusts and foundations that have generously made grants to our charity.
- 💙 Everyone that has pledged a gift in their Will to help us plan for our future.
- 💛 All the companies that donated, fundraised, sponsored our events or volunteered their time.
- 💙 All those in our community, including fundraising volunteers, groups, golf clubs and schools that support us.

Thank you to our amazing volunteers

Alexander Devine's volunteers are the lifeblood of our charity. They help us to reach more children and families, help us fundraise, provide vital support at our hospice and raise awareness of our work.

For much of 2021, the pandemic continued to impact the level of volunteering. However, our dedicated volunteers still found ways to support us and close to 2,000 hours were gifted to our charity out in the community and in our hospice.

As a charity, we simply could not do as much as we do without our volunteers and we are deeply grateful to each and every one of them for all for their time, hard work and dedication.



During 2021/22 our volunteers gifted us nearly

2,000 hours



Volunteering helped make a cost saving to our charity of more than

£25,900



140+

people generously volunteer for our charity at our hospice in Maidenhead and across our community

Thank you



So many lives are impacted by your generosity.

To every individual, business, trust, foundation, school, community group and volunteer that supported us in the last year, our heartfelt thanks.

Thank you for making sure we could be there for children and families that need us.

www.alexanderdevine.org



Registered charity number 1118947